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The Newsletter for People Interested in Multiple Myeloma

#### Dear Readers:

The 'Indoor' Picnic on June 10<sup>th</sup> was a great success with more than 40 attendees! Special thanks to our gracious host, Kevin Kluts and to our terrific volunteers who worked so hard and made it happen. Everyone had a good time, made new friends and shared information about myeloma. I wish to express my personal thanks to our supporters and donors of picnic items, raffle gifts and auction items.

Cordially, Barbara



# Multiple Myeloma Genomic MAYO Research Team Builds on Tradition of Leadership By: Dianne M. Axon

Mayo Clinic has earned its long-standing reputation as one of the best medical centers in the world for research and treatment of myeloma, and the staff of Mayo Clinic Cancer Center believes there has never been a time for more optimism in the fight against this disease. But make no mistake, it is a fight. With striking advances in medical science comes the critical need for research programs to be organized, integrated and well-supported.

The new Mayo Clinic Multiple Myeloma Team, set in Arizona, is a shining example of such a program. It builds on the already recognized international reputation of the Mayo Clinic Myeloma Program, established in Rochester, Minn., nearly a half century ago by Robert A. Kyle, M.D., and Philip R. Greipp, M.D.

Multiple myeloma is the second most common blood cancer, with 15,000 new cases diagnosed every year. It is a cancer of the plasma cells, which are found inside the bone marrow. Abnormal plasma cells multiply in a cancerous manner, causing anemia, bone destruction and reduced production of blood.

Three internationally recognized research specialists have joined Mayo Clinic Arizona to lead Mayo's multiple myeloma genomics research efforts and to expand its drug development program. All three are pioneers in the genetics of myeloma, and each brings complementary expertise to the team. They will work in collaboration and as one team with colleagues at Mayo Clinic Rochester and Mayo Clinic Jacksonville.

Peter L. Bergsagel, M.D., (Left) is known for his research in genetic changes that cause multiple myeloma. Rafael Fonseca, M.D., (Center) site director for hematologic malignancies, moved from

Mayo Clinic Rochester to Mayo Clinic Arizona to create a new center for myeloma research and care in 2004. Dr. Fonseca is

researching the clinical significance of genomics in myeloma and the implications for patient care. Alexander K. Stewart, M.B., Ch.B., (Right) is researching drugs to target genes that Drs. Bergsagel and Fonseca have discovered are involved in a majority of multiple myeloma cases. "Ultimately, our lab aims to understand the nature of tumor cells, the significance of these abnormalities and how best to use this knowledge to generate targeted therapy," says Dr. Fonseca.

The nature of biomedical research demands efficient teamwork and seamless integration. To facilitate this effort the team has moved into a unified laboratory in the new Mayo Clinic Collaboration Research Building (MCCRB) on Mayo Clinic's Arizona campus. The MCCRB is a 110,000-square-foot biomedical scientific facility the first of its kind for Mayo Clinic. The facility joins Mayo Clinic and the Translational Genomics Research Institute (TGen) in a unique partnership, and it brings together multiple strategic partners who are dedicated to scientific discovery and therapeutics.

Rapid advances in medical science pose both opportunity and challenge. New biomedical research is moving in the direction of Mayo's hallmark strengths teamwork and integration. Across Mayo Clinic's three sites - and across practice, education and research old barriers are giving way as new collaborative relationships are formed. These are important reasons to be optimistic about cancer research.

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"We are so proud and grateful for our Mayo friends, Drs. Bergsagel, Fonseca, and Stewart, who have brought so much talent and expertise to Arizona and who bring hope to all myeloma patients and their families." (Barbara Kavanagh)

#### Congratulations

On June 20<sup>th</sup>, the AZ State Legislature passed SB1442 by a 2/3 majority vote. It goes into effect in October. Congratulations to Alan and Eileen Roth. Thanks to Senator Barbara Leff for authoring the bill and to Laurie Roberts for her AZ Republic coverage of this healthcare issue.

#### **New Website Reminder**

The OFFICIAL Arizona Myeloma Network website is up and running at <a href="https://www.arizonamyelomanetwork.org">www.arizonamyelomanetwork.org</a>. News and items of interest will be posted and updated regularly.

# **Major Golf Event Coming Up**

Our major 2006 fundraising event will be the **AzMN 2nd Annual Charity Golf Tournament,** scheduled for October 5th 2006, a Thursday, at the **Raven Golf Club at Verrado** in Buckeye, Arizona. In early July, tournament details and sign-up information will be posted on our website at: www.arizonamyelomanetwork.org.

# A Family's Myeloma Story (cont. from the May/Jun AzMNewsletter)

Last month, we published mom Joanne Gomez's side of the story. In this issue we continue the Gomez family story from dad Albert Gomez's, son Michael's and daughter Priscilla's sides of the story.

# Dad's side of the Story: by Albert Gomez

"Since my wife was diagnosed with Multiple Myeloma cancer, our lives have totally changed. No one can imagine the pain and suffering that cancer has on a patient and their family. My wife was the "get up and go anywhere in the car" type to barely being able to walk, even with a walker. My kids have been the greatest



support my wife has ever received. Their unselfishness and sacrifices to ensure every effort is undertaken for their mother's well being have been remarkable. My daughter quit college to be her mom's primary caregiver and provider. My son adjusted his work schedule so he can take his mom to doctor's appointments. The simple act of taking her out for lunch or taking a ride in the car has proven to be great medicine and encouragement for her.

My wife had a bone marrow transplant almost 2 years ago, and while the progress has been great, she still has and will have back pain, but she is not bedridden like she was for almost 8 months. We love her and have learned to take care of her more than ever (not that we didn't before). There are no words to describe the anger, the pain, the financial burden and the suffering that a patient and their family go through when having such a terrible disease. While my wife at times feels she has failed us (which she absolutely has not), we will continue to see that she receives all of our attention and devotion It is now our turn to do for her what she has done for us for all of these past years. Just let it be known, mom, 'We are here and will continue to be here for you because you are our world and we love

# We love you mom, Albert"

# Our Side of the Story: by Son Michael Gomez and Daughter Priscilla Gomez

"Our mom has been through a lot since November 1, 2003. When first diagnosed, she was being treated to prevent her from having a heart attack. After that she was moved to the cancer ward and then received her first round of chemotherapy which lasted four days. She was also put on two different pain medications, which they overdosed her with and she hallucinated. They kept her on the same medications, but eventually lowered the dosage amount. The cancer ate through her bone in her right arm and she had a metal rod put in to hold her bones together and prevent them from breaking. She has gone through six rounds of Chemo, 10 rounds of radiation on her lower back and 12 rounds of radiation on her right arm. Through all of this she couldn't eat because she would get very nauseated and she lost about 40 pounds.

She is our hero for being so strong and sticking with her treatments and fighting this incurable disease. She would have had more rounds of radiation done but the doctors were doing chemo and radiation at the same time and her body couldn't handle it anymore and she got very sick. Our mom had to learn how to walk all over again due

to the fact that she was bedridden for so long her body was shutting down. She tried hard to push herself to walk again but will have to use a walker for the rest of her life to help hold herself up. Through all of her treatments she started getting a lot of anxiety. She is now being treated for that and doing much better. After we moved to Arizona she had her last round of Chemo and the doctors were ready to send her to Tucson for her bone-marrow transplant.

We hope that mom will be in full remission soon. She has lost her hair twice which is now shoulder length long and is curly which she never had before. Our mom is our life and to see her go through so much has hurt the whole family. We love her so much and want to do whatever we can to help her through her hardships. Not only is she our mom but she is also our best friend. She loves helping others without hesitation. She hangs out with us as a friend and a mom. She is one cool mom.

She is our whole life and we don't know what we'd do without her. We have always been a close family but since she was diagnosed with Multiple Myeloma, we have tried even harder to make everyday for her a very special day. We want her holidays and special occasions to be memorable for her. We all have our ways of getting through these hard times. We get mad, cry and even have our days when we don't say anything at all. Even on mom's good days we worry about her hurting or getting too tired. We still have fun by laughing together, playing games, watching movies, etc., but in the back of our minds we know things are much different now than before.

# We love you dearly mom, Michael and Priscilla"



(L-R) Michael, Albert, Priscilla, & mom Joanne Gomez at our Jun 10<sup>th</sup> Picnic at The VENU in Grayhawk.

#### Volunteers

The June 16<sup>th</sup> Volunteer Workshop at the Wellness Community of Central Phoenix was a success, as well as an opportunity for participants to share their experiences and challenges of cancer volunteering. As part of her workshop, Barbara presented some special issues that volunteers and volunteer managers face including balancing their own 'cancer' needs with that of others. All agreed that it really helps to be part of a 'team' and that we all gain as much as we

give. When one of our patients is not well, everyone pitches in to call, send notes, or visit. Truly a network of caring, which is what volunteering is all about. For more information on workshops and volunteer training, please visit our website.



June 16<sup>th</sup> Volunteer Workshop Attendees (Front Row, L-R) Barbara Kavanagh, Kay Kays, Connie Galeener. (Back Row, L-R) Melanie Holden, Diane McClure, Brenda Gregory, Amanda Hart.



June 10th Indoor Picnic Volunteers

#### 'Join our Volunteer Team!'

We are looking for interested, enthusiastic volunteers of all ages to help us with our new organization: we need people with accounting, planning and organizing, teaching, and grant writing skills, and people who want to meet other nice people and make a real contribution to the lives of myeloma patients and their families. Please contact us at the address below.

Articles from our readers are welcome and should focus on information directed towards Multiple Myeloma. They should be informative, and contain noncommercial, non-partisan, non-sectarian points of view. Articles are limited to 175 words and will be published free of charge. Editors reserve the right to edit and shorten text as necessary and to refuse article text or advertising in accordance with AzMN by-laws. Articles are due the first week of each month. Please send inquiries to:

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